

# Health Resources and Services Administration

## Programs for

# Improving Access to Quality Health Care for Children and Youth with Epilepsy

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# Division of Services for Children with Special Health Needs (DSCSHN)

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## DSCSHN Mission

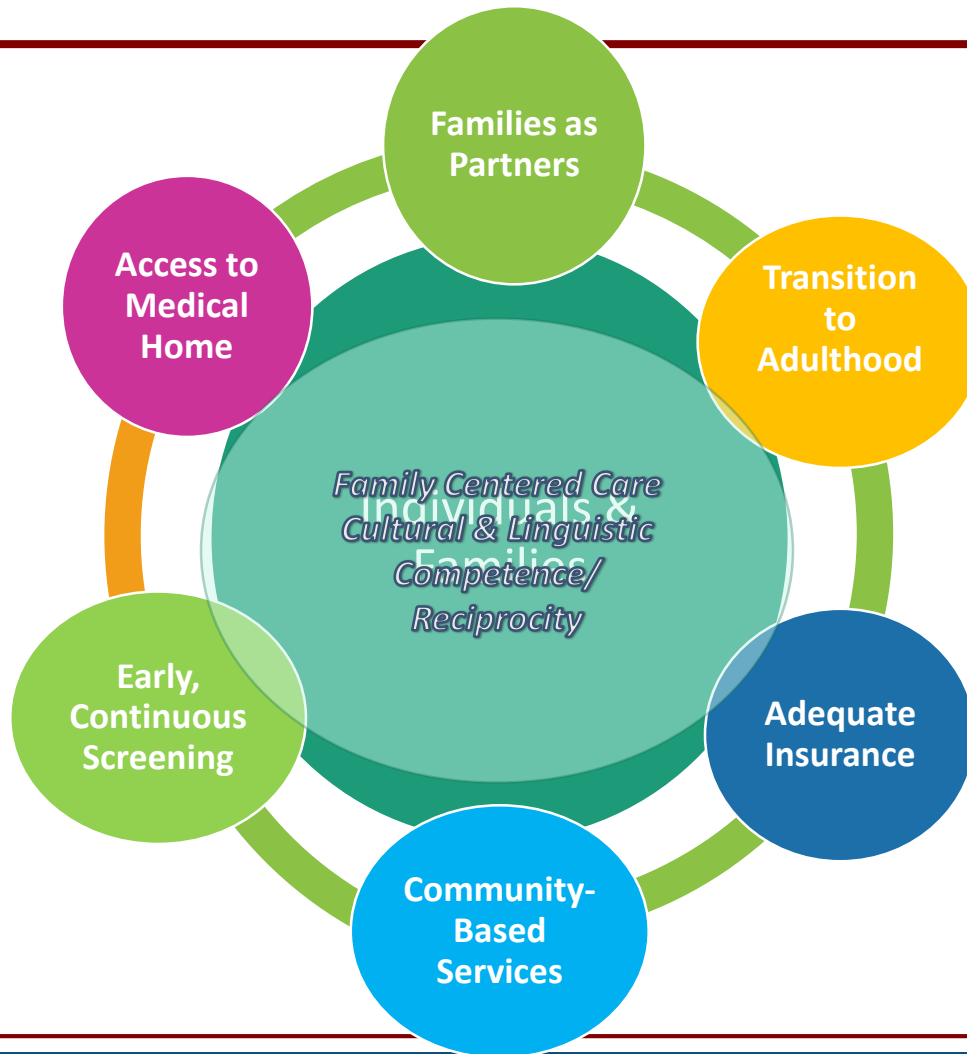
To provide national leadership to expand and strengthen access to a system of services for CYSHCN and their families as they grow and transition through adulthood.

## Vision

CYSHCN and their families will have access to a coordinated, culturally competent, community-based, comprehensive, and family-centered system of services as they grow and transition through adulthood.



# Quality Indicators of a System of Services



# Definitions

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- **Telehealth** - using technologies to support and promote long-distance clinical health care, patient and professional health-related education, public health and health administration <sup>1</sup>
- **Telemedicine** - the delivery of remote clinical services to diagnose and treat patients<sup>2</sup>
- **Medical home** – care that is accessible, family-centered, continuous, comprehensive, coordinated, compassionate, and culturally effective<sup>3</sup>
- **Family Engagement** - patients, families, their representatives, and health professionals working in active partnership at various levels across the health care system<sup>4</sup>
- **Health Care Transition** – process of changing from a pediatric to an adult model of health care<sup>5</sup>



# MCHB's Epilepsy Program

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Designed to improve access to comprehensive, coordinated health care and related services for children and youth with epilepsy residing in rural and medically underserved areas with focus on:

- Telehealth and telemedicine
- Care coordination and medical home
- Family engagement
- Health care transitions



# Previous Grants

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- **Project Access (2004-2013) - 17 awards**
- **Epilepsy program & National Coordinating Center (2013-2016) - 8 awards**

# Current Epilepsy Grants (FY2016 - FY2019)

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- **Strategic Approaches to Improving Access to Quality Health Care for Children and Youth with Epilepsy**
  - 7 grantees in MA, PA, MI, OH, TX
  - ~\$416,000/year
- **Coordinating Center for Strategic Approaches to Improving Access to Quality Health Care for Children and Youth with Epilepsy**
  - 1 cooperative agreement
  - \$650,000/year



# Purpose

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- **To improve access to coordinated and comprehensive quality care for children and youth with epilepsy with an emphasis on populations experiencing health disparities and children and youth with epilepsy residing in underserved and/or rural communities.**
  - implementing evidence-based and innovative models of telehealth and/or telemedicine (including mobile health);
  - implementing the Got Transition Six Core Elements Framework to help youth successfully transition from the pediatric to adult system of health care; and
  - facilitating outreach and education regarding epilepsy among pertinent stakeholders



# Grantee Activities & Outcomes

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- **Quality improvement learning collaboratives made up of a minimum of 7 clinical sites**
- **They will increase the number of CYE who:**
  - Receive care through a patient/family-centered medical home
  - Use comprehensive and coordinated treatment and care plans
  - Have a youth transition plan in place
  - Have access to specialized epilepsy care

# Outcomes (February 2018)

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- **Medical Home:** 97% of the CYE/family participants said that they have a place that they usually go to when they are sick/need advice for CYE's health
- **Care Coordination:** 64% of the CYE/family participants received help with care coordination
- **Family Engagement:** 82% of the CYE/family participants reported child's provider always helped them feel like a partner in the care
- **Telemedicine:** 62% of providers use telemedicine to connect with patients and 50% with other providers/specialists
- **Health care transitions:** 58% of CYE/families surveyed reported that their health care provider worked with their child on self-management (58%)



# Significant Programmatic Impact

Boston Medical Center	<ul style="list-style-type: none"> <li>Developed a program leveraging the health system volunteers to assist with care coordination within their virtual medical home model</li> <li>Invited to present to the Health System Executive Board on telehealth</li> </ul>
Cleveland Clinic	<ul style="list-style-type: none"> <li>Identified enthusiastic telehealth champion at each site</li> <li>Continue to share many telehealth visits per provider at each site to encourage “healthy” competition</li> </ul>
Children’s Hospital of Philadelphia	<ul style="list-style-type: none"> <li>Invited to present to the Health System Executive Board on transition</li> <li>Embedding daily transition workflows into sites so they will be sustained after funding ends</li> </ul>
Epilepsy Association of Western/Central Pennsylvania	<ul style="list-style-type: none"> <li>Creating individual plans for each clinical site to further implement transition aims                             <ul style="list-style-type: none"> <li>➤ Transitioned 31 youth already!</li> </ul> </li> </ul>
Epilepsy Foundation of Texas	<ul style="list-style-type: none"> <li>Developing a telemedicine pilot with clinical sites to ensure smooth implementation of new payment model</li> </ul>
Michigan Department of Health and Human Services	<ul style="list-style-type: none"> <li>Working with clinical sites to develop and integrate transition policies during in-person learning session</li> </ul>
University of Michigan/Michigan Medicine	<ul style="list-style-type: none"> <li>Building infrastructure for telemedicine and continuing to identify additional sites</li> <li>Developing transition policies into infrastructure                             <ul style="list-style-type: none"> <li>➤ Residents and patients are beginning to take notice of the transition surveys</li> </ul> </li> </ul>

# National Coordinating Center

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- **CYE Stakeholder Forum**

- Current webseries - Caring for CYE: What Primary Care Providers Need to Know

- **Project ECHO:**

- standardized curriculum on the diagnosis and management of epilepsy, while also integrating team-based care among patients, families, primary and subspecialty care practitioners in a patient/family-centered medical home

- **Access Improvement and Management for Epilepsy with Telehealth (AIM-ET):**

- Partnering pediatric neurologists with pediatric practices and training them on telehealth

# Opportunities for Improvement

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- **Care Coordination in a Medical Home**
- **Family Engagement**
- **Telemedicine/telehealth**
- **Health Care Transition**

# Next Grant Cycle

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## *Transforming Health Care for Children and Youth with Epilepsy*

- **Purpose:** To increase access to coordinated, quality health care in a patient/family-centered medical home for CYE residing in rural and/or medically underserved areas.
- **Four-year project (2019-2023)**
- **Number of awards:** Up to seven (7) grants
- **Award Amount:** Up to \$416,000 per year
- **Eligible Applicants:** Domestic public or private entity.



# Next Grant Cycle

## *Innovations in Access to Care for Children and Youth with Epilepsy*

- **Purpose:** To support those working to improve access to coordinated, comprehensive, quality care for CYE in medically underserved and/or rural areas.
- **Four-year project (2019-2023)**
- **Up to one cooperative agreement, approx. \$650,000/year**
- **Eligible Applicants:** Domestic public or private entity.



# Citations

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1. Health Resources Services Administration, Office for the Advancement of Telehealth, <https://www.hrsa.gov/rural-health/telehealth/index.html>
2. World Health Organization. (2009). Telemedicine: Opportunities and Developments in Member States. *World Health Organization eHealth Report*, 2.
3. American Academy of Pediatrics. (2002). The Medical Home. *Pediatrics*, 110(1).
4. Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient And Family Engagement: A Framework For Understanding The Elements And Developing Interventions And Policies. *Health Affairs*, 32(2), 223-231.
5. Got Transitions, <https://www.gottransition.org/providers/index.cfm>





# Contact Information

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